

Quality Standards

Palliative Care

Care for Adults With a Progressive, Life-Limiting Illness

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DRAFT

**Ontario
Palliative Care
Network**

**Health Quality
Ontario**

Let's make our health system healthier

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Summary

This quality standard addresses palliative care for people who are living with or dying from a serious, life-limiting illness, and for their family and caregivers. The goal of palliative care is to relieve pain and suffering, and to improve a person's quality of life. The quality standard focuses on care for people in all settings, including home and community, hospice, hospital, and long-term care.

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About Quality Standards

Health Quality Ontario, in collaboration with clinical experts, patients, residents, and caregivers across the province, is developing quality standards for Ontario. Health Quality Ontario has worked in partnership with the Ontario Palliative Care Network to develop this quality standard.

Quality standards are concise sets of statements that will:

- Help patients, residents, families, and caregivers know what to ask for in their care
- Help health care professionals know what care they should be offering, based on evidence and expert consensus
- Help health care organizations measure, assess, and improve their performance in caring for patients

The statements in this quality standard do not override the responsibility of health care professionals to make decisions with patients, after considering each patient's unique circumstances.

How to Use Quality Standards

Quality standards inform clinicians and organizations about what high-quality health care looks like for aspects of care that have been deemed a priority for quality improvement in the province. They are based on the best available evidence.

They also include indicators to help clinicians and organizations assess the quality of care they are delivering, and to identify gaps and areas for improvement. These indicators measure process, structure, and outcomes.

In addition, tools and resources to support clinicians and organizations in their quality improvement efforts accompany each quality standard.

For more information on how to use quality standards, contact: qualitystandards@hqontario.ca.

About This Quality Standard

Scope of This Quality Standard

This quality standard addresses care for adults with a progressive, life-limiting illness, and for their family and caregivers. It focuses on palliative care in all health settings, for all health disciplines, and in all health sectors. It includes information about general palliative care that applies to all health conditions; condition-specific palliative care may be addressed in other quality standards. Although this quality standard includes information that could apply to infants, children, and youth, a separate palliative care quality standard is being considered for these populations.

Terminology Used in This Quality Standard

In this quality standard, “health care professionals” refers to regulated professionals, such as nurses, nurse practitioners, pharmacists, physicians, physiotherapists, psychologists, occupational therapists, social workers, and speech-language pathologists. We use the term “health care providers” when we are also including people in unregulated professions, such as administrative staff, behavioural support workers, personal support workers, recreational staff, and spiritual care staff.

Why This Quality Standard Is Needed

Palliative care (also known as hospice palliative care) refers to the relief of suffering and improvement of the quality of living and dying, using a holistic approach.¹ Palliative care addresses people’s physical, psychological, social, spiritual, and practical needs, as well as their associated expectations, hopes, and fears. It helps people with a progressive, life-limiting illness and their family prepare for and manage end-of-life choices, the process of dying, and coping with loss and grief.^{1,2}

Despite the clear benefits of palliative care, there are many gaps in its delivery in Ontario, including access to palliative care services. Of the more than 95,000 people who died in Ontario between April 2014 and March 2015, approximately 54,000 received palliative care services on at least one occasion.²

Of those who received palliative care in 2014–2015, about half (48%) received it only in their last month of life, and 43% received palliative home care in their last month of life.² Receiving palliative home care has been associated with 50% reduction in the likelihood of dying in hospital.² Furthermore, about two-thirds (63%) had an unplanned visit to the emergency department in their last month of life.² This represents a missed opportunity because earlier palliative care can lead to a better quality of life for those with a progressive, life-limiting illness.²

Whether or not people are able to die in the place they choose also reveals gaps in the provision of palliative care across the province. In surveys of patients and caregivers, most say they would prefer to die at home.^{2,3} And yet, of the 54,000 people who received palliative care in 2014–2015, 65% died in hospital and 26% spent half or more of their last month of life in hospital.² More access to high-quality home care and home visits from physicians who provide palliative care would allow more people to choose the end-of-life setting they prefer.²

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Equity issues also affect the delivery of palliative care. Patients living in poorer neighbourhoods are less likely to receive palliative home care services in their last month of life (39%) than patients in the richest neighbourhoods (46%).²

The 13 quality statements that make up this quality standard are based on the best available evidence and guided by expert consensus from health care providers and people with lived experience. The statements provide guidance for areas identified by the Ontario Palliative Care Network and Health Quality Ontario's Palliative Care Quality Standard Working Group as having high potential for improvement in the way palliative care is currently provided. Each statement has accompanying indicators to help health care providers and organizations measure the quality of the care they provide, and includes details on how successful delivery can improve palliative care for people with a progressive, life-limiting illness, their family, their caregivers, health care providers, and health services at large.

Principles Underpinning This Quality Standard

This quality standard is underpinned by the principles of respect, beneficence, autonomy, and equity.

People should receive palliative care that promotes self-determination and the best interests of each person as self-defined. Person-centred care—compassionate care that respects people's wishes, beliefs, and values by promoting autonomy, dignity, and inclusion in shared decision-making as appropriate—is fundamental to an ethics-based palliative approach to care.⁴

A high-quality health system is one that provides good access, experience, and outcomes for all Ontarians, no matter where they live, what they have, or who they are.

People who have a progressive, life-limiting illness should be offered services that are respectful of their gender, sexual orientation, socioeconomic status, housing, age, background (including self-identified cultural, ethnic, and religious background), and disability. Equitable access in the health system also includes access to culturally safe care.

How We Will Measure Our Success

Health Quality Ontario has worked with the Ontario Palliative Care Network to ensure that selected measures for this quality standard are aligned with provincial measurement initiatives.

A limited number of overarching objectives are set for this quality standard; these have been mapped to performance indicators to measure the success of this quality standard as a whole:

- Percentage of people who receive in their last 12 months, 3 months, and 1 month of life:
 - Home care services (any home care and palliative-specific home care)
 - Physician home visits
- Percentage of people who had 1 or more emergency department visits in their last 12 months, 3 months, and 1 month of life
- Percentage of people identified to benefit from palliative care (or their caregivers) who rated overall care received in their last 12 months, 3 months, and 1 month of life as excellent, very good, good, fair, or poor.

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- Percentage of deaths that occurred in:
 - Hospital
 - Inpatient care
 - Emergency department
 - Complex continuing care
 - Palliative care beds
 - Long-term care
 - Community (may include home, residential hospice, retirement home, or assisted-living home)

In addition, each quality statement within this quality standard is accompanied by one or more indicators. These indicators are intended to guide measurement of quality improvement efforts related to implementation of the statement.

Quality Statements in Brief

QUALITY STATEMENT 1

Identification and Assessment of Needs

People with a progressive, life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment.

QUALITY STATEMENT 2

Access to Palliative Care

People identified to benefit from palliative care have access to palliative care support 24 hours a day, 7 days a week, according to their needs.

QUALITY STATEMENT 3

Advance Care Planning—Substitute Decision-Maker

People with a progressive, life-limiting illness know who their future substitute decision-maker is. They engage in ongoing conversations with their substitute decision-maker about their wishes, values, and beliefs, so that the substitute decision-maker is empowered to participate in the health care consent process if required.

QUALITY STATEMENT 4

Discussions and Goals of Care

To prepare them to make decisions, people identified to benefit from palliative care, their substitute decision-maker, their family, and their caregivers have early and ongoing discussions with their interprofessional health care team about their illness, prognosis, goals of care, and treatment options.

QUALITY STATEMENT 5

Individualized, Person-Centred Care Plan

People identified to benefit from palliative care collaborate with their primary care clinician and other health care professionals to develop an individualized, person-centred care plan that is reviewed and updated regularly.

QUALITY STATEMENT 6

Management of Pain and Symptoms

People identified to benefit from palliative care have their pain and other symptoms managed safely and effectively, in a timely manner.

QUALITY STATEMENT 7

Psychosocial Aspects of Care

People identified to benefit from palliative care receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs as an integral component of their care.

QUALITY STATEMENT 8

Caregiver Support

Families and caregivers of people identified to benefit from palliative care are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.

QUALITY STATEMENT 9

Education for Patients, Substitute Decision-Makers, Families, and Caregivers

People identified to benefit from palliative care, their substitute decision-maker, their family, and their caregivers are offered education about palliative care and information about available resources and supports.

QUALITY STATEMENT 10

Education for Health Care Providers and Volunteers

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

QUALITY STATEMENT 11

Setting of Care and Place of Death

People identified to benefit from palliative care, their substitute decision-maker, their family, and their caregivers have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

QUALITY STATEMENT 12

Interprofessional Team-Based Care

People identified to benefit from palliative care receive integrated care from an interprofessional team, which may include volunteers.

QUALITY STATEMENT 13

Transitions in Care

People identified to benefit from palliative care experience seamless transitions in care that are coordinated effectively between settings and health care providers.

Quality Statement 1: Identification and Assessment of Needs

People with a progressive, life-limiting illness have their palliative care needs identified early through a comprehensive and holistic assessment.

Background

Palliative care focuses on the person and their family, and on enhancing their quality of life throughout their illness, not just at the end of life.^{5,6} Palliative care should not be delayed for people with a progressive, life-limiting illness if they have physical, psychological, social, or spiritual needs during treatment.

General considerations for identifying people who would benefit from palliative care include the following: diagnosis of a progressive, life-limiting illness; disease progression; functional decline; presence of pain or other symptoms; or other effects on their full range of needs.^{7,8} A comprehensive, holistic assessment allows clinicians to determine the physical, psychological, social, cultural, legal, ethical, and spiritual needs of people with a progressive, life-limiting illness and their family or caregivers, and the services required to meet those needs.⁷ The initiation of palliative care is not determined by prognosis; it can begin as early as the time of diagnosis of a progressive, life-limiting illness, or it can be initiated during treatment, at the time of death, or during bereavement.⁷

Assessment can be conducted by any knowledgeable and skilled member of the interprofessional health care team (see Quality Statement 4 for a definition). After the initial assessment, palliative care needs should be reassessed regularly, because they evolve over time.

Sources: Institute for Clinical Systems Improvement, 2013⁷ | National Institute for Health and Care Excellence, 2015⁹ | Registered Nurses' Association of Ontario, 2011¹⁰

Definitions Used Within This Quality Statement

Progressive, life-limiting illness

A progressive, life-limiting illness is one that affects a person's health and quality of life, that gets worse over time, and that can lead to death in the near future.¹¹ Examples of illnesses that require a palliative approach to care include cancer, Alzheimer's disease and other types of dementia, congestive heart failure, chronic obstructive pulmonary disease, kidney failure, and cirrhosis of the liver.⁸

Palliative care needs

Palliative care needs can stem from any part of a person's full range of needs (physical, psychological, social, cultural, legal, ethical, or spiritual) at any stage of illness. The goal of palliative care is to help people achieve their best possible quality of life in the face of a progressive, life-limiting illness.

Identified early

Identifying the need for palliative care can occur as early as the time of diagnosis of a progressive, life-limiting illness. Palliative care is not limited to the end-of-life phase, and it is not restricted to specific diseases or conditions.

Comprehensive and holistic assessment

This includes a full examination of the domains of care associated with illness and bereavement^{10,12}: disease management, physical, psychological, social, cultural,⁷ legal, ethical,⁷ spiritual, practical, end-of-life, loss, and grief. Validated tools used for assessment include the Edmonton Symptom Assessment System,^{7,10} the Palliative Performance Scale, and the Brief Pain Inventory.

What This Quality Statement Means

For Patients, Families, and Caregivers

You should be assessed to determine what palliative care or supports you need. Your care team will ask questions about your physical and mental health, your support system, and any other needs you feel you have, to understand how best to help you.

For Clinicians

Assess people with a progressive, life-limiting illness to determine whether they would benefit from palliative care. Perform and document a comprehensive, holistic assessment that considers the individual's diagnosis; disease progression; functional decline; presence of pain or other symptoms; and other effects on their full range of needs. Assessment should be repeated regularly.

For Health Services

Ensure that systems, processes, and resources are in place in all health settings for clinicians to identify and assess people's palliative care needs. This includes access to assessment or screening tools and timely access to palliative care.

Quality Indicators

Process Indicator

Percentage of people identified to benefit from palliative care who have a documented assessment of their palliative care needs (physical, psychological, social, cultural, legal, ethical, and spiritual)

- Denominator: total number of people identified to benefit from palliative care
- Numerator: number of people in the denominator who have a documented assessment of their palliative care needs (physical, psychological, social, cultural, legal, ethical, and spiritual)
- Data source: local data collection

Structural Indicator

Percentage of health care professionals who have tools to identify people who would benefit from palliative care and assess their needs

Outcome Indicator

Average number of days between receiving first palliative care service and death

- Calculation: can be measured as mean, median, or distribution
- Data source: administrative data

Quality Statement 2: Access to Palliative Care

People identified to benefit from palliative care have access to palliative care support 24 hours a day, 7 days a week, according to their needs.

Background

People with a progressive, life-limiting illness may have complex needs that require advice, resources, treatment, or support, and those needs may change over time.¹³ The needs of people with a progressive, life-limiting illness (and those of their families and caregivers) often arise during the evening, overnight, or on the weekend. Palliative care support should be available whenever the person needs it, at any time of day or night. Appropriate palliative care support is determined based on a person's individual needs and does not necessarily mean continuous, around-the-clock care.

The availability of coordinated and integrated palliative care support from a knowledgeable and skilled care team is important to meet patient, family, and caregiver needs.¹³ All people, regardless of their diagnosis, prognosis, or location, should be able to access palliative care support appropriate to their needs at any time.

Source: Consensus statement

Definitions Used Within This Quality Statement

Palliative care support

Palliative care support consists of health advice, resources, treatment, and other assistance provided by the health care team to meet a person's palliative care needs. Support can come in many forms, including a telephone call with a registered nurse; a number to call when pain is not well managed; or a home visit from a primary care clinician.

What This Quality Statement Means

For Patients, Families, and Caregivers

You should be able to get palliative care support whenever you need it, day or night.

For Clinicians

Ensure that people identified to benefit from palliative care have access to palliative care support 24 hours a day, 7 days a week, as needed.

For Health Services

Ensure that systems, processes, and resources are in place so that people identified to benefit from palliative care can receive palliative care support whenever they need it, at any time of day or night.

Quality Indicators

Structural Indicator

Local availability of palliative care support that is accessible 24 hours a day, 7 days a week

Draft—do not cite. Report is a work in progress and could change following public consultation.

Outcome Indicator

Percentage of people identified to benefit from palliative care (or their caregivers) who state that they are able to receive community palliative care support, including after-hours care, when needed

- Denominator: total number of people identified to benefit from palliative care (or their caregivers)
- Numerator: number of people in the denominator who state that they are able to receive community palliative care support, including after-hours care, when needed
- Data source: local data collection

Quality Statement 3: Advance Care Planning—Substitute Decision-Maker

People with a progressive, life-limiting illness know who their future substitute decision-maker is. They engage in ongoing conversations with their substitute decision-maker about their wishes, values, and beliefs, so that the substitute decision-maker is empowered to participate in the health care consent process if required.

Background

Advance care planning includes choosing and confirming a future substitute decision-maker who can communicate a person's wishes, values, and beliefs about care, and make decisions when that person is no longer able to do this for themselves. The Ontario *Health Care Consent Act* outlines a hierarchical list of people who would automatically be considered a substitute decision-maker when a person is incapable of making decisions about their own care.¹⁴ If a person is not satisfied with their automatic substitute decision-maker, they can formally appoint someone else to be their substitute decision maker using a Power of Attorney for Personal Care.

Ongoing communication between the person with a progressive, life-limiting illness and their substitute decision-maker is important so that the substitute decision-maker is aware of their role and can participate fully as an advocate, acting in the person's best interests if or when they are no longer able to communicate.⁷ Advance care planning is relevant for every person and family, and these conversations should be revisited regularly as a person's condition changes.

Sources: Institute for Clinical Systems Improvement, 2013⁷ | National Institute for Health and Care Excellence, 2015⁹ | Ontario Health Technology Advisory Committee, 2014¹⁵

Definitions Used Within This Quality Statement

Advance care planning

Advance care planning is ongoing and dynamic, because a person's preferences may change over time.¹ It may be initiated at any point, and may involve people who are currently healthy. In advance care planning, a mentally capable person identifies their substitute decision-maker by confirming the automatic substitute decision-maker from the hierarchy list (<https://www.ontario.ca/laws/statute/96h02#BK25>) in the *Health Care Consent Act* or by choosing someone else using a Power of Attorney for Personal Care.¹⁴ They then share their wishes, values, and beliefs with the substitute decision-maker, and discuss how they would like to be cared for if they become incapable of giving or refusing consent.

Substitute decision-maker

A substitute decision-maker is a person who makes care and treatment decisions on another person's behalf if or when that person becomes incapable of making decisions for themselves.¹ The substitute decision-maker makes decisions based on their understanding of the person's wishes, or, if these are unknown or not applicable, makes choices that are consistent with the person's known values and beliefs and in their best interests.

Wishes, values, and beliefs

A person's wishes, values, and beliefs convey who the person is, how they would make choices for themselves, what they think is important, and what would influence their decision-making.^{11,16} Values are the principles on which a person's morality or spirituality is based. If a person is incapable of making or communicating choices for themselves, the substitute decision-maker (not the health care professional) interprets their wishes.

Health care consent

Health care consent refers to an informed and contextualized decision involving a mentally capable person and a health care provider as outlined in the Ontario *Health Care Consent Act*.¹⁴ Health care providers who propose a treatment must obtain informed consent from a capable patient (or their substitute decision-maker, if they do not have the mental capacity). A discussion about consent must address the person's present condition; available treatment options; risks, benefits, side effects, and alternatives to treatment; and what would happen without the proposed treatment.¹

What This Quality Statement Means

For Patients, Families, and Caregivers

The law designates a substitute decision-maker if you do not choose someone. Your care team should ensure that you know who your substitute decision-maker is, if you have not appointed one yourself. If there is someone you want to make decisions on your behalf if you aren't able to do so, you should tell your care team as soon as possible. This person will be your substitute decision-maker. You should talk to your substitute decision-maker about your wishes, values, and beliefs so they can make the right decisions for you.

For Clinicians

Ensure that your patients know who the law considers to be their substitute decision-maker(s) and how they can appoint someone else if they wish. Encourage patients to plan for their care—to think about their values, wishes, and beliefs, and then share those with their family and their substitute decision-maker.

For Health Services

Ensure that information and resources are available for people to learn about Ontario laws related to advance care planning, substitute decision-making, and health care consent.

Quality Indicators

Process Indicators

Percentage of people identified to benefit from palliative care who know who their substitute decision-maker is

- Denominator: total number of people identified to benefit from palliative care
- Numerator: number of people in the denominator who know who their substitute decision-maker is
- Data source: local data collection

Draft—do not cite. Report is a work in progress and could change following public consultation.

Percentage of people identified to benefit from palliative care who know who their substitute decision-maker is and state that they have spoken with their substitute decision-maker about their wishes, values, and beliefs

- Denominator: total number of people identified to benefit from palliative care who know who their substitute decision-maker is
- Numerator: number of people in the denominator who state that they have spoken with their substitute decision-maker about their wishes, values, and beliefs
- Data source: local data collection

Quality Statement 4: Discussions and Goals of Care

To prepare them to make decisions, people identified to benefit from palliative care, their substitute decision-maker, their family, and their caregivers have early and ongoing discussions with their interprofessional health care team about their illness, prognosis, goals of care, and treatment options.

Background

People with a progressive, life-limiting illness (and/or their substitute decision-maker) should have a discussion with their interprofessional health care team to address the person's goals of care, obtain health care consent, and inform decision-making when illness is advanced.¹ The purpose of these discussions is to outline the person's values, beliefs, wishes, perception of quality of life, and the things they characterize as meaningful and important.¹ Discussions about personal goals of care supports health care decision-making that is aligned with the person's values, beliefs, and wishes.

These discussions are also important opportunities to ensure that patients, families, and caregivers have a good understanding of the person's illness. Other elements for discussion include the person's understanding of their health condition, their prognosis, and the likely course of events if their goals of care are applied to treatment decisions. The discussion provides a foundation for decision-making and will often lead to the development of a care plan (see Quality Statement 5 for a definition). When individuals lack the capacity to make decisions, health care professionals must work with substitute decision-makers to determine an appropriate course of action. Informed consent must be obtained for any treatment or care plan from either the patient or the substitute decision-maker.⁷

Sources: Institute for Clinical Systems Improvement, 2013⁷ | National Institute for Health and Care Excellence, 2015⁹ | Ontario Health Technology Advisory Committee, 2014¹⁵ | Registered Nurses' Association of Ontario, 2011¹⁰

Definitions Used Within This Quality Statement

Family

Family consists of those closest to a person in terms of knowledge, care, and affection, and may include biological family, family through marriage, or family of choice and friends.¹¹ The person with the progressive, life-limiting illness defines their family and who will be involved in their care.

Caregiver

A caregiver is an unpaid person who provides care and support in a nonprofessional capacity, such as a family member, a friend, or anyone else identified by the person with a progressive, life-limiting illness. Other terms commonly used to describe this role include care partner, informal caregiver, family caregiver, carer, or primary caregiver.

Goals of care

A person's goals of care are their overall priorities and health expectations for care and are based on their personal values, wishes, and beliefs. Choosing goals of care includes a consideration of quality of life, and a person's goals are characterized by what they find meaningful and important.¹ Possible goals of care could be cure of disease, prolongation of life, relief of suffering, optimized quality of life, maintenance of control, achieving a good death, and/or support for family and loved ones.¹⁷

Interprofessional health care team

An interprofessional health care team consists of health care providers with different types of training and skills who work together to provide care based on a person's care plan.¹¹ The composition of the team varies depending on the services needed. An interprofessional team may include physicians, nurses, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, and volunteers. Other disciplines may be part of the team if resources permit.

What This Quality Statement Means

For Patients, Family, and Caregivers

You and your care team should talk about your illness and how it could progress. You should also talk about your goals and treatment options. Talking about your wishes will help your care team make sure you get the type of care you want.

For Clinicians

Talk to your patients about their illness, prognosis, goals of care, and treatment options. Early and ongoing discussions are beneficial for ensuring that patients' values, beliefs, and wishes are aligned with the care provided.

For Health Services

Ensure that health care professionals are given adequate education and training so they feel equipped to have meaningful conversations with their patients about their illness, prognosis, goals of care, and treatment options.

Quality Indicators

Process Indicator

Percentage of people identified to benefit from palliative care who have had documented discussions with someone in their interprofessional health care team about their illness, prognosis, goals of care, and treatment options

- Denominator: total number of people identified to benefit from palliative care
- Numerator: number of people in the denominator who have had a documented discussion about their illness, prognosis, goals of care, and treatment options with someone from their interprofessional health care team
- Data source: local data collection

Outcome Indicator

Percentage of people identified to benefit from palliative care (or their caregivers) who state that discussions with their interprofessional health care team members about their illness, prognosis, goals of care, and treatment options helped them understand and make treatment decisions

- Denominator: total number of people identified to benefit from palliative care (or their caregivers) who had discussions with their interprofessional health care team members about their illness, prognosis, goals of care, and treatment options
- Numerator: number of people in the denominator who state that those discussions helped them understand and make treatment decisions
- Data source: local data collection

Quality Statement 5: Individualized, Person-Centred Care Plan

People identified to benefit from palliative care collaborate with their primary care clinician and other health care professionals to develop an individualized, person-centred care plan that is reviewed and updated regularly.

Background

Creating and documenting an individualized, person-centred care plan improves the quality and efficiency of care.¹⁸ Care plans place the patient at the focal point and guide the care that is provided. The use of care plans promotes communication, continuity of care, and coordination of care.¹⁸ The plan should include the person's goals and wishes, treatment decisions and consent, preferred care setting, current and anticipated care needs, and the resources required to meet those needs.⁹ The care plan is documented in the medical record so that all team members have access to the information.⁹ The person's ability and desire to be involved in making decisions may change as their condition changes, and the care plan should be updated accordingly.⁹

Source: National Institute for Health and Care Excellence, 2015⁹

Definitions Used Within This Quality Statement

Individualized, person-centred care

Individualized, person-centred care consists of care and treatment that is customized for each person based on their values, wishes, goals, and unique health needs.¹⁹ The person with the progressive, life-limiting illness drives the care provided; a person-centred approach involves a partnership between patients and their health care professionals.

Care plan

A care plan is also known as a plan of treatment.¹⁴ It is a written document that describes a person's health needs and goals and the care that will be provided to meet them.^{1,11} A care plan is developed by one or more health care professionals, deals with one or more health problems, and may deal with health problems that the person is likely to experience in the future, given their current health condition. A care plan provides for the administration of treatments or courses of treatment and may also provide for withholding or withdrawing treatment.¹⁴ The person receiving care or the substitute decision-maker must provide informed consent to their care plan.

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should work with you to create a care plan that fits with your values, wishes, and goals. Your care team will use the plan to provide palliative care that meets your needs. This care plan should be updated as often as you need.

For Clinicians

Collaborate with people who would benefit from palliative care to create and document a care plan that reflects their individual values, wishes, and goals of care. A plan should be created at the start of care and then reviewed and updated as needed.

For Health Services

Ensure that all health care settings have the tools, systems, processes, and resources in place for health care professionals and people who would benefit from palliative care to create and document individualized, person-centred care plans.

Quality Indicators

Process Indicators

Percentage of people identified to benefit from palliative care (or their caregivers) who state that they were involved in decisions about their care

- Denominator: total number of people identified to benefit from palliative care (or their caregivers)
- Numerator: number of people in the denominator who state that they were involved in decisions about their care
- Data source: local data collection; similar question is available in the CaregiverVoice Survey
- Note: the CaregiverVoice Survey is administered in select settings to measure caregivers' experiences when caring for a person in their last 3 months of life

Percentage of people identified to benefit from palliative care (or their caregivers) who state that they had an opportunity to review and update their care plan (plan of treatment) when they needed

- Denominator: total number of people identified to benefit from palliative care (or their caregivers) who have a care plan (plan of treatment)
- Numerator: number of people in the denominator who state that they had an opportunity to review and update their care plan (plan of treatment) when they needed
- Data source: local data collection

Outcome Indicator

Percentage of people identified to benefit from palliative care (or their caregivers) who have a care plan (plan of treatment) in their medical record

- Denominator: total number of people identified to benefit from palliative care
- Numerator: number of people in the denominator who have a care plan (plan of treatment) in their medical record
- Data source: local data collection

Quality Statement 6: Management of Pain and Symptoms

People identified to benefit from palliative care have their pain and other symptoms managed safely and effectively, in a timely manner.

Background

Management of pain and other symptoms is an important part of high-quality palliative care and an integral component of the individualized care plan.^{7,9} It is important to consider nonpharmacological and pharmacological management throughout a person's illness.

Not all patients who receive palliative care will experience the same pain or other symptoms, so it is important to assess the level and range of severity. Possible causes of symptoms, the person's preferences, and the benefits and harms of intervention should also be assessed. If pain or other symptoms are identified, they should be managed promptly and effectively, and any reversible causes should be treated.⁹ Pain and symptom management requires ongoing reassessment to ensure the efficacy of any interventions and monitoring for changes.⁹

Sources: Institute for Clinical Systems Improvement, 2013⁷ | National Institute for Health and Care Excellence, 2015⁹ | Registered Nurses' Association of Ontario, 2011¹⁰

Definitions Used Within This Quality Statement

Pain and other symptoms

Pain and other symptoms are the effects of illness or treatment. Symptoms associated with progressive, life-limiting illness may include the following:

- Agitation⁹
- Anxiety^{7,10}
- Breathlessness⁹
- Constipation¹⁰
- Dehydration⁹
- Delirium^{9,10}
- Depression⁷
- Nausea^{9,10}
- Noisy respiratory secretions⁹
- Pain^{7,9,10}
- Vomiting^{9,10}

Pain and other symptoms can also affect activities of daily living (e.g., bathing, mobility, continence).

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should assess you for pain and other symptoms. They should manage pain or other symptoms quickly and effectively.

For Clinicians

Assess patients for pain and other symptoms. Ensure the delivery of high-quality pain and symptom management.

For Health Services

Provide adequately resourced systems and services to ensure that health care professionals can conduct pain and symptom assessments and offer nonpharmacological and pharmacological treatments. Ensure that systems, processes, and resources are in place so that patients have access to timely and effective pain and symptom management.

Quality Indicators

Process Indicator

Percentage of people identified to benefit from palliative care (or their caregivers) who state that their pain and other symptoms were assessed regularly

- Denominator: total number of people identified to benefit from palliative care (or their caregivers)
- Numerator: number of people in the denominator who state that their pain and other symptoms were assessed regularly
- Data source: local data collection

Structural Indicator

Availability of appropriate tools to assess pain and other symptoms for people identified to benefit from palliative care

Outcome Indicator

Percentage of people identified to benefit from palliative care (or their caregivers) who state that they received excellent support to relieve their pain and other symptoms

- Denominator: total number of people identified to benefit from palliative care (or their caregivers)
- Numerator: number of people in the denominator who state that they received excellent support to relieve their pain and other symptoms
- Data sources: local data collection; similar question is available in the CaregiverVoice Survey, and alternative question is available in the InterRAI [Resident Assessment Instrument] tools
- Note: the CaregiverVoice Survey is administered in select settings to measure caregivers' experiences when caring for a person in their last 3 months of life

Quality Statement 7: Psychosocial Aspects of Care

People identified to benefit from palliative care receive timely psychosocial support to address their mental, emotional, social, cultural, and spiritual needs as an integral component of their care.

Background

When people face a progressive, life-limiting illness, psychosocial issues may go undetected or untreated, and this can affect their quality of life.⁷ Pain and other symptoms may be the initial focus of treatment, but psychosocial well-being should also be assessed. A psychosocial assessment can facilitate the identification of any supports a person needs during their illness.

Psychosocial issues can manifest as physical symptoms (e.g., pain, constipation, nausea). Therefore, it is important that health care professionals are aware of the physiological symptoms that may be an indication of depression and anxiety.⁷

Illness and the prospect of dying affect and can also be affected by the meaning and purpose of a person's life. A focus on spirituality may include questions about meaning, value, and relationships, and can lead to spiritual concerns, questions, or distress. Patients may draw on their spirituality as they make health care decisions and as they cope with illness and the experience of dying.⁷

Sources: Institute for Clinical Systems Improvement, 2013⁷ | Registered Nurses' Association of Ontario, 2011¹⁰

Definitions Used Within This Quality Statement

Psychosocial support

Psychosocial support involves care related to a person's state of mental, emotional, social, cultural, and spiritual well-being.^{7,10}

Mental and emotional needs

Mental and emotional needs relate to a person's psychological and emotional well-being. Issues of concern for a person with a progressive, life-limiting illness may include fear, worry, insomnia, panic, anxiety, nervousness, paranoia, or lack of energy.¹⁰

Social needs

Social needs relate to a person's relationships with their family, community, and network (friends, acquaintances, and coworkers).⁷ Social needs may relate to family structure and location, family dynamics, communication, social and cultural networks, perceived social support, work and school settings, finances, sexuality, intimacy, living arrangements, caregiver availability, medical decision-making, access to transportation, medications, equipment and nutrition, community resources, or legal issues.

Cultural needs

Cultural needs relate to the beliefs and preferences that come from one's social and ethnic identity. Cultural needs may include linguistic needs, health beliefs and behaviours, traditions, rituals, or cultural barriers to accessing health care.

Spiritual needs

Spiritual needs relate to “the way individuals seek and express meaning and purpose, and the way they experience their connectedness to the moment, to self, to others, to nature, and to the significant or sacred.”⁷ Spiritual needs may include religious practices or philosophical reflection.

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should assess your mental, emotional, social, cultural, and spiritual well-being. Your needs should be addressed as part of your care plan and according to your wishes, values, and goals of care.

For Clinicians

Ensure that the overall psychosocial well-being of people with a progressive, life-limiting illness is assessed, and that their needs are incorporated into the care plan.

For Health Services

Ensure that resources are available for health care professionals to assess and meet the psychosocial needs of people with a progressive, life-limiting illness.

Quality Indicators

Process Indicator

Percentage of people identified to benefit from palliative care (or their caregivers) who state that their psychosocial needs were assessed regularly

- Denominator: total number of people identified to benefit from palliative care
- Numerator: number of people in the denominator who state that their psychosocial needs were assessed regularly
- Data source: local data collection

Percentage of people identified to benefit from palliative care (or their caregivers) who state that they received psychosocial support to address their identified mental, emotional, social, cultural, and spiritual needs

- Denominator: total number of people identified to benefit from palliative care with psychosocial needs (or their caregivers)
- Numerator: number of people in the denominator who state that they received psychosocial support to address their mental, emotional, social, cultural, and spiritual needs
- Data source: local data collection
- Note: consider measuring separately by each type of psychosocial need or group together as an overall measure of psychosocial support

Outcome Indicator

Percentage of people identified to benefit from palliative care (or their caregivers) who state that they received excellent support in addressing their psychosocial needs (mental, emotional, social, cultural, and spiritual)

- Denominator: total number of people identified to benefit from palliative care who have psychosocial needs (or their caregivers)

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- Numerator: number of people in the denominator who state that they received excellent, very good, good, fair, or poor support in addressing their psychosocial needs (mental, emotional, social, cultural, and spiritual)
- Data source: local data collection; similar question is available in the CaregiverVoice Survey
- Note: consider measuring separately by each type of psychosocial need or group together as an overall measure of psychosocial support
- Note: the CaregiverVoice Survey is administered in select settings to measure caregivers' experiences when caring for a person in their last 3 months of life

Quality Statement 8: Caregiver Support

Families and caregivers of people identified to benefit from palliative care are offered ongoing assessment of their needs, and are given access to resources, respite care, and grief and bereavement support, consistent with their preferences.

Background

Families and caregivers of people with a progressive, life-limiting illness have needs across multiple domains. Families and caregivers benefit from support as they manage medical information, learn how to provide care, and develop coping strategies to deal with medical care, personal care, psychological/social/spiritual care, loss, grief, and bereavement. General advice and support, along with education to improve coping and communication skills for caregivers, are associated with decreased distress.¹⁵

Source: Consensus statement

Definitions Used Within This Quality Statement

Family

Family consists of those closest to a person in terms of knowledge, care, and affection, and may include biological family, family through marriage, or family of choice and friends.¹¹ The person with the progressive, life-limiting illness defines their family and who will be involved in their care.

Caregiver

A caregiver is an unpaid person who provides care and support in a nonprofessional capacity, such as a family member, a friend, or anyone else identified by the person with a progressive, life-limiting illness. Other terms commonly used to describe this role include care partner, informal caregiver, family caregiver, carer, or primary caregiver.

Caregiver assessment

A caregiver assessment includes an examination of physical, psychological, social, spiritual, cultural, and environmental considerations.¹¹ The assessment may relate to the caregiver's needs and preferences, as well as associated treatment, care, and support. Use of validated tools may help clinicians explore the caregiver's values and preferences, well-being, burden, skills and abilities, and resources.¹⁰

What This Quality Statement Means

For Patients, Families, and Caregivers

Your care team should ask your family members and caregivers about the help they need.

For Clinicians

Offer holistic assessment and appropriate support to the family and caregivers of people with a progressive, life-limiting illness.

For Health Services

Ensure that systems are in place to offer holistic assessment and appropriate support to the family and caregivers of people with a progressive, life-limiting illness.

Quality Indicators

Process Indicators

Percentage of caregivers of people identified to benefit from palliative care who state that they and the family members received as much help and support as they needed from health and supportive services or bereavement services

- Denominator: total number of caregivers of people identified to benefit from palliative care
- Numerator: number of people in the denominator who state that they and the family members received as much help and support as they needed from health and supportive services or bereavement services
- Data source: local data collection; similar question is available in the CaregiverVoice Survey
- Note: the CaregiverVoice Survey is administered in select settings to measure caregivers' experiences when caring for a person in their last 3 months of life

Percentage of family members and caregivers of people identified to benefit from palliative care who state that they were offered ongoing assessment of their needs

- Denominator: total number of family members and caregivers of people identified to benefit from palliative care
- Numerator: number of people in the denominator who state that they were offered ongoing assessment of their needs
- Data source: local data collection

Percentage of caregivers who state that, after the patient's death, they talked to someone from health and supportive services or bereavement services about their feelings regarding the illness and death, if they were interested in those services

- Denominator: total number of caregivers of people who died of a progressive, life-limiting illness, who were interested in health and supportive services or bereavement services
- Numerator: number of people in the denominator who state that, after the patient's death, they talked to someone from health and supportive services or bereavement services about their feelings regarding the illness and death
- Data source: local data collection; question is available in the CaregiverVoice Survey
- Note: the CaregiverVoice Survey is administered in select settings to measure caregivers' experiences when caring for a person in their last 3 months of life

Quality Statement 9: Education for Patients, Substitute Decision-Makers, Families, and Caregivers

People identified to benefit from palliative care, their substitute decision-maker, their family, and their caregivers are offered education about palliative care and information about available resources and supports.

Background

For people with a progressive, life-limiting illness, their substitute decision-makers, and their family and caregivers, education plays a vital role in increasing their knowledge about their care, providing reasonable expectations about illness progression and palliative care and preparing them for the decisions they will need to make.^{10,20} Education can increase a person's sense of self-control and well-being.²⁰ Education about symptom management and coping strategies improves symptom control for patients at the end of life and improves quality of life for caregivers.¹⁵ Education can be delivered in a variety of formats, from in-person interaction to written materials, online self-training, or hands-on skills practice and problem-solving.²⁰

Sources: Ontario Health Technology Advisory Committee, 2014¹⁵ | Registered Nurses' Association of Ontario, 2011¹⁰

Definitions Used Within This Quality Statement

Education

Education topics may include symptom management, coping strategies, available community resources, system navigation, health decision-making, medication, death and dying, vigil practices, and care after death.^{10,20,21}

What This Quality Statement Means

For Patients, Families, and Caregivers

You, your family, and your caregivers should be given information about palliative care from the care team. You should also be given information about resources and supports, such as hospice volunteers, support groups, and grief counselling.

For Clinicians

Provide education about palliative care to patients, their families, and their caregivers, and offer information about available resources and supports.

For Health Services

Ensure that educational resources and tools about palliative care are available for health care professionals, patients, their families, and their caregivers.

Quality Indicators

Process Indicators

Percentage of people identified to benefit from palliative care (or their caregivers) who state that a health care professional helped them understand palliative care and provided information about available resources and supports

- Denominator: total number of people identified to benefit from palliative care (or their caregivers)
- Numerator: number of people in the denominator who state that a health care professional helped them understand palliative care and provided information about available resources and supports
- Data source: local data collection

Percentage of caregivers of people identified to benefit from palliative care who stated that a health care professional helped them understand what to expect and how to prepare for each stage of the journey toward the end of life

- Denominator: total number of caregivers of people identified to benefit from palliative care (limited to one caregiver per person)
- Numerator: number of people in the denominator who stated that a health care professional helped them understand what to expect and how to prepare for each stage of the journey toward the end of life
- Data source: local data collection; similar question is available from the CaregiverVoice Survey
- Note: the CaregiverVoice Survey is administered in select settings to measure caregivers' experiences when caring for a person in their last 3 months of life

Structural Indicator

Local availability of resources and tools for health care professionals to provide education about palliative care to patients, families, and caregivers

Quality Statement 10: Education for Health Care Providers and Volunteers

People receive palliative care from health care providers and volunteers who possess the appropriate knowledge and skills to deliver high-quality palliative care.

Background

People with a progressive, life-limiting illness, families, and caregivers have complex needs; for this reason, those who provide care should have comprehensive palliative care education. Education that focuses on improving communication skills, knowledge, and attitudes about palliative care has a positive effect on a person's experience of palliative care.¹⁵ Education materials and programs should be tailored to the health care provider's role and responsibilities.

Sources: Ontario Health Technology Advisory Committee, 2014¹⁵ | Registered Nurses' Association of Ontario, 2011¹⁰

Definitions Used Within This Quality Statement

Knowledge and skills

Education should include communication skills, assessment and care planning, advance care planning, and symptom management.⁹ It may also include the following¹⁰:

- Care of the family and caregiver
- Principles and models of palliative care
- Assessment and management of pain and other symptoms
- Spiritual or existential issues
- Effective and compassionate communication
- Advocacy and therapeutic relationship-building
- Decision-making and advance care planning
- Ethical issues
- Knowledge of relevant legislation
- Interprofessional practice and competencies
- Self-care, including coping strategies and self-exploration of death and dying
- End-of-life issues in vulnerable populations (people with mental health issues, people who are homeless/vulnerably housed, and people who are incarcerated)
- The social and cultural context of death and dying
- Dying trajectories and signs of impending death
- Grief, bereavement, and mourning
- Roles of grief and bereavement educators, clergy, spiritual leaders, and funeral directors

Health care providers and volunteers^{22,23}

These include regulated health care professionals and unregulated care providers. In Ontario, regulated health professions (e.g., physicians, nurses, occupational therapists) are accountable to their regulatory colleges, which ensure that professionals provide health services in a safe, professional, and ethical manner. Unregulated care providers (e.g., palliative care volunteers, personal support workers) may assist with or perform certain aspects of care traditionally

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provided by regulated health care professionals, based on their role and employment setting, and are accountable to their employers.

What This Quality Statement Means

For Patients, Families, and Caregivers

You should receive care from a knowledgeable team that works together to meet your needs and goals of care.

For Clinicians

You should receive education to effectively provide care for people with a progressive, life-limiting illness in accordance with your role.

For Health Services

Ensure that systems, processes, and resources are in place for health care providers and volunteers to receive the education necessary to provide high-quality palliative care.

Quality Indicators

Process Indicator

Percentage of health care providers and volunteers who provide palliative care and who have received palliative care education appropriate to their role

- Denominator: total number of health care providers and volunteers who provide palliative care
- Numerator: number of providers in the denominator who have a record of receiving palliative care education appropriate to their role
- Data source: local data collection
- Potential stratification: health care providers, volunteers

Outcome Indicator

Percentage of health care providers and volunteers who provide palliative care and who state that they have the knowledge and skills to provide palliative care

- Denominator: total number of health care providers and volunteers who provide palliative care
- Numerator: number of people in the denominator who state that they have the knowledge and skills to provide palliative care
- Data source: local data collection
- Potential stratification: health care providers, volunteers

Quality Statement 11: Setting of Care and Place of Death

People identified to benefit from palliative care, their substitute decision-maker, their family, and their caregivers have ongoing discussions with their health care professionals about their preferred setting of care and place of death.

Background

A person's preferences for where to receive palliative care and where to die depend on an interplay of factors associated with the illness, the individual, and the environment. A person's preferred setting of care and place of death should be part of a care plan (see Quality Statement 5: Individualized, Person-Centred Care Plan) that reflects the person's wishes, goals, and needs. Different care settings and places of death should be considered, including the person's home (usual place of residence), a long-term care home, a residential hospice, or an inpatient palliative care unit. A number of factors increase the feasibility and likelihood of a home death, including the availability of multidisciplinary home palliative care, early referral to palliative care, patient preferences, having a caregiver, and the caregiver's ability to cope.¹⁵ Discussions about setting of care and place of death should be ongoing; their choice may change depending on their status.

Sources: National Institute for Health and Care Excellence, 2015⁹ | Ontario Health Technology Advisory Committee, 2014¹⁵

Definitions Used Within This Quality Statement

Setting of care

The setting of care is the place where palliative care is provided.¹¹ Care settings may include the person's home, a hospice or inpatient palliative care unit, a long-term care home, a correctional facility, or for a person who is homeless or vulnerably housed, a shelter or the street.

Preferred setting of care and place of death

Discussions with health care professionals about setting of care and place of death should include the following¹⁵:

- Interprofessional palliative care in the person's place of residence
- Time between referral to palliative care services and death
- Type of underlying disease
- Functional status
- Frequency of hospitalizations during the last year of life
- Living arrangements (e.g., living with someone, living alone)
- Presence of a caregiver
- Caregiver's ability to cope
- Patient or family preference for place of death
- Consideration of previous advance care planning conversations
- Nursing home and hospital bed availability
- Availability of resources to support the patient's physical and psychological needs, where they live, during the end-of-life period

What This Quality Statement Means

For Patients, Families, and Caregivers

You and your care team should talk about where you would like to be cared for (for example, at home, in a home-like environment called a hospice, or in a long-term care home). Your wishes may change over time, so on an ongoing basis, you should discuss your preferences, how your disease impacts your ability to perform normal daily activities, whether you are living with someone who can help you, and whether other help you may need is available. You should be given information about care in different locations to help you make the best choices for you, your family, and other informal caregivers.

For Clinicians

Provide information about options for setting of care and place of death to people who would benefit from palliative care, their family, and their caregivers. This information should include all of the factors outlined in the definitions.

For Health Services

Ensure that resources and tools are available to support discussions about preferred setting of care and place of death between health care professionals and people who would benefit from palliative care.

Quality Indicators

Process Indicator

Percentage of people identified to benefit from palliative care whose preferred setting of care and place of death is recorded in their care plan

- Denominator: total number of people identified to benefit from palliative care
- Numerator: number of people in the denominator whose preferred setting of care and place of death is recorded in their care plan
- Data source: local data collection

Outcome Indicators

Percentage of people identified to benefit from palliative care whose medical records indicate that they died in their preferred place of death

- Denominator: total number of people identified to benefit from palliative care who died and had their preferred place of death recorded in their care plan
- Numerator: number of people in the denominator who died in their preferred place of death
- Data sources: local data collection (similar indicator is currently measured in the Client Health and Related Information System for palliative home care clients)

Percentage of caregivers of people identified to benefit from palliative care who think that the person they cared for died in the right place

- Denominator: total number of caregivers of people identified to benefit from palliative care who died (limited to one caregiver per person)
- Numerator: number of people in the denominator who think that the person they cared for died in the right place

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- Data source: local data collection; similar question is available from the CaregiverVoice Survey
- Note: the CaregiverVoice Survey is administered in select settings to measure caregivers' experiences when caring for a person in their last 3 months of life

Quality Statement 12: Interprofessional Team-Based Care

People identified to benefit from palliative care receive integrated care from an interprofessional team, which may include volunteers.

Background

The model of care used to deliver health services can affect the quality of the care received. Team-based, integrated care facilitates continuity for people with a progressive, life-limiting illness, their family, and their caregivers.¹⁰ The team-based model of care must include a nurse or physician with the knowledge and skills to deliver palliative care.¹⁵ The team may also include social workers, psychologists, spiritual advisors, personal support workers, other care providers, and volunteers. The services provided by the team include symptom management, psychosocial care, care plan development, advance care planning conversations, goals of care discussions, and care coordination.¹⁵

Sources: Ontario Health Technology Advisory Committee, 2014¹⁵

Definitions Used Within This Quality Statement

Integrated care

Health services are managed and delivered so that people receive care that is coordinated across the health system, at all levels and settings, and according to the patient's needs throughout their life course.²⁴ Integrated care involves the delivery, management, and organization of services for diagnosis, treatment, care, rehabilitation, and health promotion. Integration of care brings about better access, quality, user experience, and efficiency.

Interprofessional health care team

An interprofessional health care team consists of health care providers with different types of training and skills who work together to provide care based on a person's care plan.¹¹ The composition of the team varies depending on the services needed. An interprofessional team may include one or more physicians, nurses, social workers, psychologists, spiritual care providers, pharmacists, personal support workers, and volunteers. Health care professionals from other disciplines may be part of the team if resources permit.

Team-based care

Team-based care refers to the provision of health services by a group of health care providers who work collaboratively with patients, family, and caregivers to meet their shared goals of care within and across settings of care.

What This Quality Statement Means

For Patients, Families, and Caregivers

You should receive care from a knowledgeable team that works together to meet your needs and goals of care.

For Clinicians

Collaborate with other health care providers, volunteers, family, and caregivers to meet the needs of people receiving palliative care.

Draft—do not cite. Report is a work in progress and could change following public consultation.

For Health Services

Provide adequately resourced systems and services to ensure that health care professionals, volunteers, and caregivers can work in teams to provide integrated palliative care.

Quality Indicators

Process Indicator

Percentage of people who receive palliative care (or their caregivers) who state that they have received care from an interprofessional team of health care providers, including a physician or nurse

- Denominator: total number of people who receive palliative care
- Numerator: number of people in the denominator who state that they have received care from an interprofessional team of health care providers, including a physician or nurse
- Data source: local data collection

Quality Statement 13: Transitions in Care

People identified to benefit from palliative care experience seamless transitions in care that are coordinated effectively between settings and health care providers.

Background

Transitions in care that are based on patient needs involve logistical arrangements to move a person from one care setting to another or from one care provider to another.²⁵ Transitions in care should be coordinated among knowledgeable and skilled health care professionals who are familiar with the person's clinical status, goals of care, care plan, and health information needs.²⁵

Timely and effective communication is essential to prevent problems that may occur if services and supports are not well integrated (e.g., delayed transfers, readmissions, or poor care).²⁶ Identifying a member of the care team to be accountable for care coordination supports a smooth transition between settings and prevents communication failures.²⁶ Information-sharing between settings to ensure all health care providers are aware of the person's current condition is part of effective and coordinated communication. All information-sharing during care transitions must consider legislated privacy and security requirements.²⁵

Families and caregivers also play a vital role in transitions. Health care professionals should have informed discussions with them about available care settings. Health care professionals should work together, and with the patient, their family and their caregivers, to ensure that transitions in care are timely, appropriate, and safe.

Source: Consensus statement

Definitions Used Within This Quality Statement

Seamless transition

A seamless transition consists of a set of actions designed to ensure the safe and effective coordination and continuity of care when patients experience a change in health status, health care professional, or location (within, between, or across settings).^{25,27}

Coordinated effectively

Coordinated care is the deliberate organization of patient care activities between two or more participants involved in a patient's care (including the patient) to facilitate the appropriate delivery of health care services. Organizing care involves coordinating people and resources to carry out required patient care activities and is often managed by exchanging information among those responsible for the various aspects of a patient's care.^{25,27}

What This Quality Statement Means

For Patients, Families, and Caregivers

When you change care settings or care providers (for example, if you return home after being in hospital), your care team should work with you to make sure that you and your new care team members have the information you need (such as information about your medication) and that you receive the services you need (such as plans for follow up).

For Clinicians

Ensure that people moving between care settings or care providers experience coordinated and seamless transitions. This includes facilitating communication between settings and other related processes.

For Health Services

Ensure that systems, processes, and resources are in place to facilitate communication and information-sharing between care providers and care settings during transitions.

Quality Indicators

Process Indicator

Percentage of people identified to benefit from palliative care whose care plan documents a member of their team responsible for care coordination

- Denominator: total number of people identified to benefit from palliative care
- Numerator: number of people in the denominator whose care plan documents a member of their team responsible for care coordination
- Data source: local data collection

Outcome Indicator

Percentage of people identified to benefit from palliative care (or their caregivers) who state that they experienced seamless transitions between care settings

- Denominator: total number of people identified to benefit from palliative care (or their caregivers)
- Numerator: number of people in the denominator who state that they experienced seamless transitions between care settings
- Data source: local data collection; similar question is available from the CaregiverVoice Survey
- Note: the CaregiverVoice Survey is administered in select settings to measure caregivers' experiences when caring for a person in their last 3 months of life

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Ahmed Jakda (co-chair)

Provincial Clinical Co-Lead, Ontario Palliative Care Network, Physician, Grand River Hospital

Melody Boyd (co-chair)

Operations Director, Mental Health Program and Simcoe Muskoka Regional Cancer Program, Royal Victoria Regional Health Centre

Brenda Albuquerque-Boutilier

Lived Experience Advisor

Nancy Cooper

Director of Quality and Performance, Ontario Long-Term Care Association, Adjunct Professor, Institute of Health Policy, Management and Evaluation, University of Toronto

Deborah Evans

Clinical Nurse Specialist, Pain and Symptom Management Team, Juravinski Cancer Centre, Hamilton Health Sciences

Edward Fitzgibbon

Physician, Division of Palliative Care, University of Ottawa (The Ottawa Hospital)

Patty Greve

Registered Nurse, ARCH Connect, Outreach Nurse Coordinator, ARCH Hospice

Cathy Hecimovich

Past Chief Executive Officer, Central West Community Care Access Centre

Andrew Ignatieff

Lived Experience Advisor

Julia Johnston

Nurse Practitioner, Palliative Care, Mississauga Halton Local Health Integration Network

Jo-Anne Kershaw

Lived Experience Advisor

Ruth MacKay

Hospice Volunteer

Ramona Mahtani

Physician, Palliative Care, Mount Sinai Hospital, Sinai Health System

Debbie Maskell-Collins

Social Worker, Algoma District Cancer Program, Sault Area Hospital

Amy Montour

Physician, Regional Palliative Care Multi-Disciplinary Co-Lead, Hamilton Niagara Haldimand Brant LHIN, Cancer Care Ontario

Giulia-Anna Perri

Medical Director, Palliative and End of Life Care, Baycrest Health Sciences

Mary Alice Policchio

Chaplain, F.J. Davey Home Long-Term Care Facility

Katherine Ross

Nursing Supervisor, Carefor Health and Community Services

Declan Rowan

Family Physician, Regional Primary Care Lead, Petawawa Centennial Family Health Team, Champlain Regional Cancer Program, Cancer Care Ontario

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Sarah Shallwani

Occupational Therapist, CBI Home Health

Kathy Simpson

Palliative Care Lead Physician, Thunder Bay Regional Health Science Centre

Pamela Simpson

Pharmacist, Manager, Robinson's Pharmasave

Marcia Sokolowski

Co-Director of Ethics, Baycrest Health Sciences, Associate Professor, Department of Medicine, University of Toronto

Peter Tanuseputro

Family Physician, Public Health and Preventative Medicine Physician, Investigator, Bruyère Research Institute, Associate Scientist, Ottawa Hospital Research Institute, Assistant Professor, Division of Palliative Care, Department of Medicine, University of Ottawa

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About Health Quality Ontario

Health Quality Ontario is the provincial advisor on the quality of health care. We are motivated by this single-minded purpose: **Better health for all Ontarians.**

Who We Are

We are a scientifically rigorous group with diverse areas of expertise. We strive for complete objectivity, and look at things from a vantage point that allows us to see the forest and the trees. We work in partnership with health care providers and organizations across the system, and engage with patients themselves, to help initiate substantial and sustainable change to the province's complex health system.

What We Do

We define the meaning of quality as it pertains to health care, and provide strategic advice so all the parts of the system can improve. We also analyze virtually all aspects of Ontario's health care. This includes looking at the overall health of Ontarians, how well different areas of the system are working together, and most importantly, patient experience. We then produce comprehensive, objective reports based on data, facts and the voices of patients, caregivers and those who work each day in the health system. As well, we make recommendations on how to improve care using the best evidence. Finally, we support large-scale quality improvements—by working with our partners to facilitate ways for health care providers to learn from each other and share innovative approaches.

Why It Matters

We recognize that, as a system there is much to be proud of, but also that it often falls short of being the best it can be. Plus, certain vulnerable segments of the population are not receiving acceptable levels of attention. Our intent at Health Quality Ontario is to continuously improve the quality of health care in this province regardless of who you are or where you live. We are driven by the desire to make the system better, and by the inarguable fact that better has no limit.

About the Ontario Palliative Care Network

The Ontario Palliative Care Network is a partnership funded by the Ministry of Health and Long-Term Care and led by CCO, the Local Health Integration Networks, Health Quality Ontario, and the Quality Hospice Palliative Care Coalition of Ontario. It is putting patients and families at the centre of every decision and strengthening hospice palliative care services across Ontario. This work is person-centred, focusing on supporting the provision of quality hospice palliative care for all Ontarians, regardless of their age or disease type. The Ontario Palliative Care Network will help to ensure that hospice palliative care in Ontario is high-quality, sustainable, accessible, continuous, and person-centred.

Draft—do not cite. Report is a work in progress and could change following public consultation.

Quality Standards

Looking for more information?

Visit our website at hqontario.ca and contact us at qualitystandards@hqontario.ca if you have any questions or feedback about this guide.

Health Quality Ontario

130 Bloor Street West, 10th Floor
Toronto, Ontario
M5S 1N5

Tel: 416-323-6868

Toll Free: 1-866-623-6868

Fax: 416-323-9261

Email: QualityStandards@hqontario.ca

Website: hqontario.ca

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